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Patient #: __ __ __

Application Date: __ __ __

Screening and Natural History of Patients with Fibrous Dysplasia and the McCune - Albright Syndrome

Referring Physician Information

Last Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

First Name [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Street [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

City [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

State [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

Zip Code [ ][ ][ ][ ][ ][ ]

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Home Number (Country Code) [ ][ ][ ][ ]-(Area Code/City Code) [ ][ ][ ][ ]-(Number) [ ][ ][ ][ ][ ][ ][ ][ ][ ]

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Specialty [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

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Patient Demographic Information

Patient's Last Name [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Patient's First Name [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Patient's Middle Name [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Street [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

City [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

State [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Zip Code [ ] [ ] [ ] [ ] [ ] [ ]

Country [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Home Number (Country Code) (Area Code/City Code) (Number)
[ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Work Number [ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

Fax Number [ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ]-[ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ] [ ]

E-mail [ ]

Date of Birth [ ] [ ] -[ ] [ ] -[ ] [ ]
mo day yr

Gender [ ] male [ ] female

Race [ ]American Indian or Alaskan Native
[ ] Asian or Pacific Islander
[ ] Black [ ] Hispanic [ ] White

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Fibrous Dysplasia History

1. When was your patient diagnosed with FD? Date: [ ] / [ ] / [ ]

2. What were the symptoms at the time?
   (check all that apply)

[ ] pain	[ ] fracture	[ ] deformity
[ ] limp	[ ] swelling	[ ] abnormal growth
[ ] visual or hearing loss	[ ] headache	[ ] none

3. How was the diagnosis made?
   (check all that apply)

   [ ] x-ray

   [ ] CT

   [ ] MRI

   [ ] bone scan

   [ ] medical history (for example: bone disease in the setting of MAS)

   [ ] biopsy

   [ ] other, explain:

   _____

   _____

   _____

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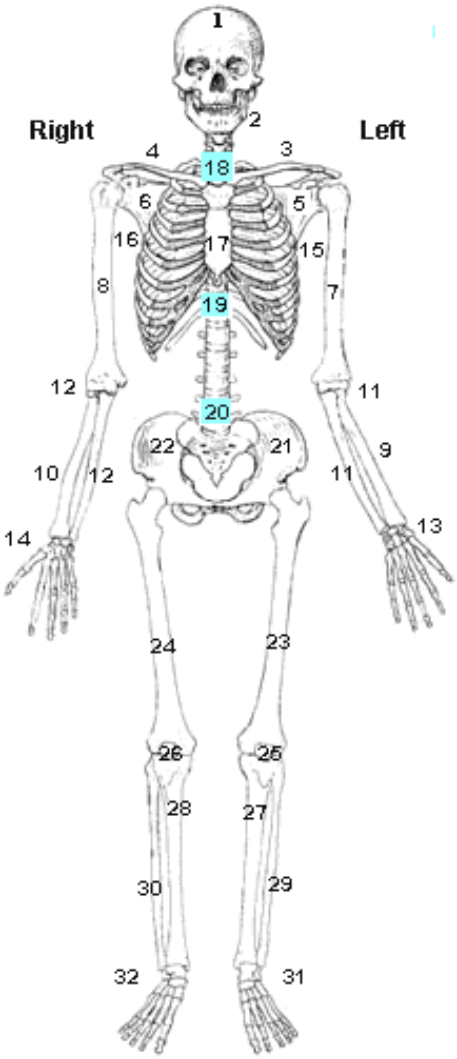
4. What bones were involved at the time of diagnosis? Indicate on the skeleton



[ ] 1.Skull
[ ] 2.Mandible (Jaw)
[ ] 3.Left Clavicle (Collar bone)
[ ] 4.Right Clavicle (Collar bone)
[ ] 5.Left Scapula (shoulder blade)
[ ] 6.Right Scapula (shoulder blade)
[ ] 7.Left Humerus (Upper arm)
[ ] 8.Right Humerus (Upper arm)
[ ] 9.Left Radius (Forearm)
[ ] 10.Right Radius (Forearm)
[ ] 11.Left Ulna (Forearm)
[ ] 12.Right Ulna (Forearm)
[ ] 13.Left Hand/Wrist
[ ] 14.Right Hand/Wrist
[ ] 15.Left Ribs (1-12)
[ ] 16.Right Ribs (1-12)
[ ] 17.Sternum (breast bone)
[ ] 18.Cervical Spine (Neck)
[ ] 19.Thoracic Spine
[ ] 20.Lumbar spine (lower back)
[ ] 21.Left Pelvis
[ ] 22.Right Pelvis
[ ] 23.Left Femur (Thigh)
[ ] 24.Right Femur (Thigh)
[ ] 25.Left Patella (knee Cap)
[ ] 26.Right Patella (knee Cap)
[ ] 27.Left Tibia (Lower leg large bone)1
[ ] 28.Right Tibia (Lower leg large bone)1
[ ] 29.Left Fibula (Lower leg small bone)
[ ] 30.Right Fibula (Lower leg small bone)
[ ] 31.Left Foot/Ankle
[ ] 32.Right Foot/Ankle

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5. Did your patient have symptoms prior to the diagnosis?

[ ] yes [ ] no [ ] Not Available

6. When did your patient first have symptoms (approximate date)?

Date: [ ] / [ ] / [ ]

7. What are your patients current symptoms?

[ ] pain [ ] fracture [ ] deformity
[ ] limp [ ] swelling [ ] abnormal growth
[ ] visual or hearing loss [ ] headache [ ] none

8. Has your patient had any fractures?

[ ] yes [ ] no

9. Has your patient had any spinal problems?

[ ] scoliosis [ ] kyphosis [ ] Vertebral Fracture
[ ] Low Back Pain [ ] other, explain: _____
[ ] none

10. Has your patient had any neurological complications (such as loss of vision) from his/her FD?

[..] Vision [ ] Hearing [ ] Muscle weakness – body
[ ] Muscle weakness –face [ ] Sensory [ ] None

11. Does your patient have any craniofacial deformity?

[ ] yes [ ] no

12. Does your patient have any dental abnormalities related to their bone disorder?

[ ] yes [ ] no

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13. Does your patient have a discrepancy in the length of his/her legs and arms?

[ ] yes [ ] no
(if no, go on to question 19)

Please provide limb measurements:
Clinical measurements:

Measurements in centimeters	Left	Right
UM (umbilicus to medial malleoulus)		
AM (ASIS to Medial Malleolus)		

14. Does your patient have osteomalacia?

[ ] yes [ ] no

Age at diagnosis _____

Was treatment provided? [ ] yes [ ] no

Treatment :
[ ] phosphorus
[ ] calcitriol
[ ] other vitamin D prep
[ ] Other :_____

Effect of its treatment on pain:

[ ] increase [ ] decrease

Effect of its treatment on fractures:

[ ] increase [ ] decrease

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15. Does you patient have any bleeding dyscrasias?

[ ] tendency to bleed [ ] tendency to thrombose [ ] No dyscrasias

16. Has your patient required any transfusions? [ ] yes [ ] no [ ] don't know

(if patient it male skip to next page)
17. Has your patient entered menopause?
[ ] yes [ ] no

What age did the patient start menopause? _____

What caused the menopause to start?
[ ] spontaneous (natural)
[ ] the result of surgery

[display only if above checked]
Were her ovaries removed?

[ ] yes [ ] no

[ ] the result of chemotherapy
For what reason was it received?
_____

18. Was there any change (improvement or worsening) in her bone disease with menopause? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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McCune-Albright Syndrome History

1. Has your patient been diagnosed with the McCune-Albright syndrome (MAS)?

   [ ] yes [ ] no

2. Does your patient have café-au-lait spots (areas of darkened skin, the color of coffee with cream in it)?

   [ ] yes [ ] no

   Do the café-au-lait spots have smooth or irregular borders?

   [ ] irregular [ ] smooth

   How many spots at birth _____?

   How many spots now _____?

   Which side of your patient's body is the majority of the café-au-lait spots?

   [ ] right [ ] left [ ] fairly equal

   Is there any correlation between the side of his/her body on which most of his/her café-au-lait spots are and his/her FD?
   [ ] no relationship [ ] same side [ ] opposite sides

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3. Does or did your patient have precocious puberty? [ ] yes [ ] no
Age of onset: _____

Has your patient been on therapy or therapies (medicines and/or surgeries) for the precocious puberty in the past?

[ ] Medical [ ] Surgical [ ] None

4. Does you patient currently have precocious puberty?

[ ] yes [ ] no

Is your patient currently on therapy for this condition?
[ ] Medical [ ] Surgical [ ] None

Is it effective?
[ ] yes [ ] no

5. At what age did the patient start puberty: _____

6. Was there any change (improvement or worsening) in his/her bone disease with or around the start of his/her puberty? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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7. Has your patient been diagnosed with thyroid disease?

[ ] yes [ ] no [ ] not available

At what age did it start? _____

What is the nature of his/her thyroid disease?
- [ ] hyperthyroidism (elevated thyroid function)
- [ ] hypothyroidism (low thyroid function)
- [ ] benign thyroid nodule(s)
- [ ] thyroid cancer

8. Has your patient received any treatment for his/her thyroid disease?

[ ] Medical [ ] Surgical [ ] None

9. Was there any change (improvement or worsening) in his/her bone disease with the onset of his/her thyroid disease? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

10. Was there any change (improvement or worsening) in your patient's bone disease during the treatment of the thyroid disease?.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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11. Has your patient been diagnosed with hypersecretion of any pituitary hormones? That is high growth hormone (causing acromegaly), high prolactin, high ACTH (causing Cushing's disease), high thyroid stimulating hormone (causing hyperthyroidism)?

[ ] yes [ ] no [ ] Not available

If yes, which hormone(s)?

Hormone	Age started	Treatment
[ ] growth hormone	_____	_____
[ ] prolactin	_____	_____
[ ] ACTH	_____	_____
[ ] TSH	_____	_____

What effect did the elevation of the hormone have on his/her FD? From the list below please indicate whether the symptom got better, worse or had no change.

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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12. Has your patient been diagnosed as having elevated secretion of hormone(s) from the adrenal gland (cortisol, aldosterone)? Elevated secretion of cortisol causes Cushing's disease and elevated secretion of aldosterone causes severe hypertension with low potassium.

Hormone	Age diagnosed	Treatment
[ ] cortisol	_____	_____
[ ] aldosterone	_____	_____
[ ] None		

If yes, what effect did the elevation of the hormone have on his/her bone disease?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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13. Has your patient been diagnosed as having an elevation of parathyroid hormone? Elevations of this hormone cause elevations in his/her blood calcium (hypercalcemia).

[ ] yes [ ] no [ ] Don't Know

At what age was it diagnosed: _____.

What type of treatment was provided:
_____

What effect did it have on his/her bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

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14. Has your patient been diagnosed as having hypophosphatemia (low levels of phosphate in his/her blood)?

[ ] yes [ ] no [ ] Don't Know

What age was it diagnosed: _____.

What type of treatment was provided:
_____

What effect did it have on his/her bone disease symptoms?

Symptom	Better	Worse	No change
Pain	[ ]	[ ]	[ ]
Limp	[ ]	[ ]	[ ]
Vision/hearing	[ ]	[ ]	[ ]
Fracture	[ ]	[ ]	[ ]
Swelling	[ ]	[ ]	[ ]
Headache	[ ]	[ ]	[ ]
Deformity	[ ]	[ ]	[ ]
Abnormal growth	[ ]	[ ]	[ ]

15. Has your patient been diagnosed as having rickets or osteomalacia?

[ ] yes [ ] no [ ] Don't Know

16. Does your patient have or ever had low vitamin D?

[ ] yes [ ] no [ ] don't know

17. Does your patient have any renal problems?

[ ] nephrolihiasis
[ ] proteinuria
[ ] aminoaciduria
[ ] calciuria (sp?)
[ ] Phosphaturia
[ ] insufficiery(sp?)
[ ] hyperfiltration (sp?)
[ ] none

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Other Questions

18. Does your patient have any unrelated (unrelated to FD or MAS as far as you know) medical problems?

    [ ] yes [ ] no

    Please list them:

    1. _____
    2. _____
    3. _____
    4. _____
    5. _____

19. List any other medications which you patient is taking:

    1. _____
    2. _____
    3. _____
    3. _____
    4. _____

End